



National Council for Child Health and Wellbeing: The Cost of Caring 2025

9 July 2025



Family Fund

Helping disabled children

Key findings



The Financial Cost of Caring



“My son relies heavily on medical machines to keep him alive so our bills are way above average. Then comes winter and he suffers with his lungs and the heating has to be on 24/7 for him. And the bills just get higher and higher.



**87% of parent/carers said
they do not have any
savings or investments**



“We try to spend all our money on our son's special education. Soon we have debts and financial problems. We have no savings. We need many more things, but the most important is one to one speech therapy. My son is 4 years old and nonverbal”



“The household support fund isn't open yet. I keep desperately checking. Liam* has lots of medical equipment and struggles regulating his temperature. This time of year is the worst for us 😞. He has a feed tube that needs charging daily, a through floor lift hoist, bed and bath seat - all electric”



82% respondents said that they have some form of debt



“We lost significant family members over the last four years, Jayden’s* dad, my mum, dad, nan and granddad. So I have not had anyone to help out with childcare, loaning money for bills, lifts for appointments etc. So I am in debt. I live on 3 credit cards juggling paying one or another”



**Doing without has
become a way of life**



“My daughter gets everything she needs as she needs so much to feel calm and settled. I work as much as I can around caring for my daughter but I go without everything. I don’t earn enough for me”



Paid work doesn't work for many parents and carers of disabled children



“My days are unpredictable. I can be called to collect my child from his specialist school more than 3 times a week and most employers are not empathetic to this so I’ve lost work because my responsibility to child means I’m unreliable to most employers”



Caring commitments do not easily combine with paid employment



“My child having a school placement - full time - us having ample respite and funding. I had to leave work due to my child having no school placement and my ill health”



The complex pattern of disability and caring can prevent paid employment



“I have 4 adults / kids with additional needs or physical conditions and have additional needs myself so it would be too difficult to manage all and work.”



Lack of Suitable Childcare: wraparound and holiday provision with trained providers



"Having more childcare providers that can work evenings. Most settings close at 6pm or don't take disabled children. The only SEN holiday childcare club somewhere fairly close to me has now closed down due to lack of funding"



Lack of Suitable Childcare for specific age groups - teenagers



**“Job vacancies that are local to me
and understand my own disabilities,
and childcare that is suitable for my
teenage child”**



Lack of Suitable Childcare: trust



**“Having someone I trust and trained
to look after my son”**



The human cost of caring



The human cost of caring

- **The stresses on parent/carers are evident with 28% of them showing wellbeing scores that are indicative of probable clinical depression.**



“I am really struggling just with day to day living costs for myself and my children. It’s having a massive impact on my mental health and also my children’s as sometimes I have to go without a meal so they can both eat”



The human cost of caring

- **The emotional cost of care is compounded by feelings of isolation and loneliness.**
 - **46% parent/carers say they often feel isolated from others**
 - **41% often feel that they feel left out**



“Since the diagnosis of autism all the family members who we used to see don’t bother with us anymore so it’s literally just me and my husband .. my mum used to help out a lot but now she has ill health and I’m now her unpaid carer as well.”



**Carers need care
themselves – but often
struggle to find it**



“Respite care at weekends and holidays to be able to work in half terms, and have a break in order to not feel so exhausted”



Julia's story



What needs to change?



- The additional costs of disability – both financial and emotional - **must be properly recognised in the support available to families.**
- Policy must take into account that, for many families, **increasing paid work is not a viable solution to poverty.**
- Childcare and respite services **must be available, affordable, and tailored to children with complex needs.**
- **The well-being of carers must be prioritised.** Without this, families risk reaching crisis point, with long-term social and economic consequences.



**No family should have to choose
between heating, eating
and caring for their child**



Download the report here:



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